APPENDIX C: POWERPOINT PRESENTATIONS BY PANELISTS

GERALDINE TONICH

Parent Representative
Family Resource Specialist
Family Ties
Westchester County, NY

Federal Interdepartmental Meeting:

Children & Adolescents with Developmental Disabilities & Emotional &/or Substance Abuse Disorders

"A Parent's Story"

Geraldine Tonich
Family Ties, Parent Coordinator



GERALDINE TONICH

A Parent's Story

Matthew, Age 9

- Early Years
 - Birth to Age 3
 Opportunities
 - 3 Years to 5 Years Pre-Ed.
 - · Age 5

Missed

Committee on School Special

Diagnosis of Autism



Family Support Advocacy

Introduction to Family Support (Family Ties) through a Community Based System of Care.

- 1. Advocacy
- 2. Peer Support
- 3. Sibling Group



GERALDINE TONICH

Systemic Issues

- Role of Pediatrician
- School Response
- Autism "Catch 22":

Autism diagnosis may prevent a child from receiving mental health treatment services



On-Going Challenges

- Effect on other children in the family
- Families Need In-Home Help
- Difficulty in finding a child psychiatrist for a younger child

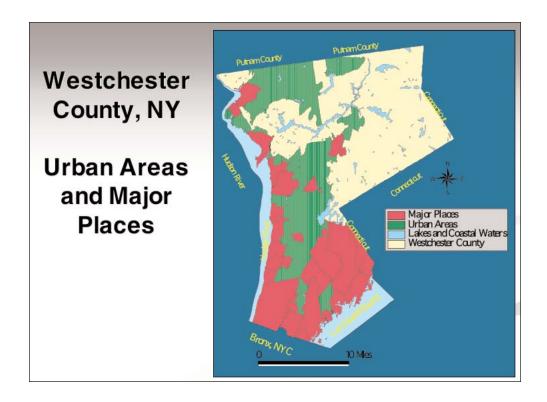


Director, Children's Mental Health Westchester County Department of Community Mental Health

Federal Interdepartmental Meeting:

Children & Adolescents with
Developmental Disabilities & Emotional
&/or Substance Abuse Disorders

Myra Alfreds, Director
Children's Mental Health Services
Westchester County, New York



Challenges & Differences

MR/DD

- State Driven
- Higher Ratio
 Service
 Coordination
- Programmatic Family Support
- Dispute Resolution
- Adult Driven
- Life long

Mental Health

- County Driven
- Lower Ratio
 Intensive Case
 Management
- Community-Based Family Support
- Collaborative Model
- Child/Adult
- Time Limited



Cross System Issues

- Pediatricians do not routinely screen for Mental Health & Developmental Disabilities.
- Parents must often choose one system or the other.



Definition of a System of Care

A comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and their families.

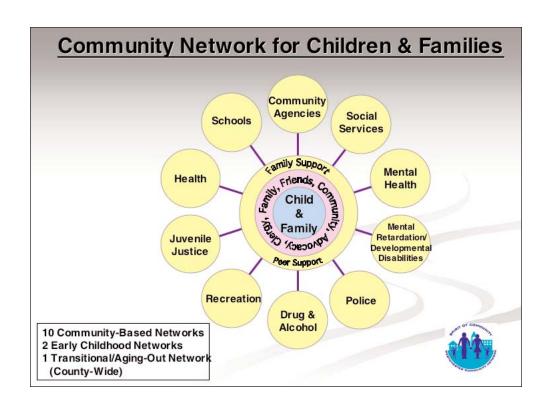


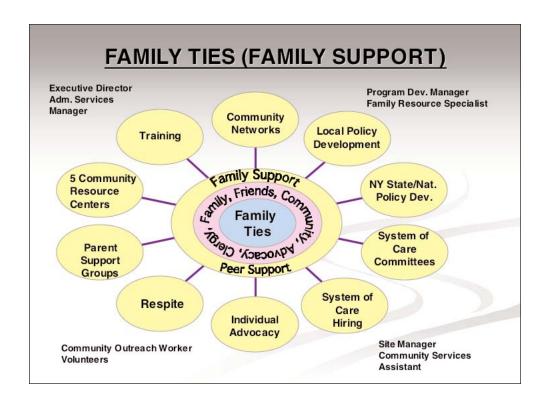
System of Care Principles & Values

- Community-Based
- Family Driven
- Culturally Competent
 Flexibly Funded
- Team Developed & Supported
- Never Give Up

- Individualized
- Strength Based
- Supports & Services that Every Child Needs







Westchester County System of Care Strategies

- Ongoing Cross System Planning
- Collaborative Care Coordination
- Annual Multi-Session Training & Resource Book for Children
- Peer Support/Supervision



FEDERAL RECOMMENDATIONS

- Put the Needs of Children with Co-Occurring Disorders Front & Center in the Federal Agenda. Utilize the New Freedom Commission Report as a Social Marketing tool and foster Policy Development, Planning, & Partnerships with Parents & Professionals across all Federal Agencies;
- Use the System of Care Approach as a Best Practice Model. Include all children who could benefit from help from more than one system, not only those who meet strict eligibility criteria. Support the establishment of independent Wraparound Committees that are separately funded and could replace the current "dispute resolution" committees;
- Create real incentives in all applicable Federal Funding Streams, such as Medicaid, Medicaid Waivers, as well as in federal grant programs to insure that children with Co-Occurring Disorders are a priority for services.

For additional information



www.westchestercommunitynetwork.co

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Directory, Child, Adolescent and Family Services Department of Mental Health Vermont Department of Health

Vermont's Experience With Dual Diagnosis

By
Charlie Biss
Director of Child, Adolescent And Family Unit
State of Vermont

Issues Experienced

- Increased incidence of Autism, Pervasive Developmental Disorder, and dual diagnosed.
- Lack of leadership to claim this vulnerable population.

Issues Experienced Continued

- Mental Health and Developmental Disabilities have a long history of cultural differences, turf battles, diversity of funding and lack of cross-training.
- Developmental Disabilities is not a full mandated partner in Act 264 (interagency coordination law).
- High number of dual diagnosed children in child welfare, Juvenile Justice, out-of-state educational placement, and hospital.

Issues Experienced Continued

- These children are usually identified at times of significant family and school crises.
- There is a lack of trained professionals to make effective differential diagnoses and to treat and support these children and their families.

Action Taken

- Invited Developmental Disabilities to become part of Act 264.
- Interagency groups at the local and state level discussed the policy and treatment issues for this population and their families were invited to these discussions.

Action Taken Continued

- Encouraged treatment teams to develop appropriate plans of care for these children regardless of the funding.
- Discussed the poor outcomes as a result of not serving these children well:
 - inappropriate hospitalization
 - out-of-state placements by school
 - custody relinquishment to child welfare
 - incarceration by Juvenile Justice.

Action Taken Continued

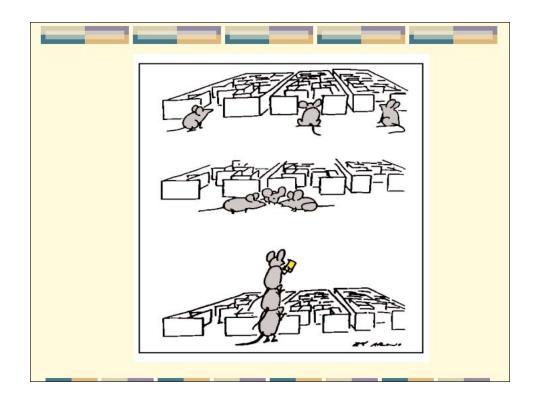
- Mental Health and Developmental
 Disabilities jointly applied for and received state funds for children with Pervasive Developmental Disorders.
- Mental Health works collaboratively with early childhood professionals (e.g., Part C) and with pediatricians to identify early onset of social/emotional problems.

Lessons Learned

- System of Care model works for these children.
- Training professionals is large infrastructure issue.
- Early detection is essential.

Lessons Learned Continued

- System of Care philosophy takes a long time to learn.
- This population is growing in numbers and we must act now!
- Interagency councils at the state and local level that are mandated to meet regularly can address barriers.



Best Practice

• Interagency collaboration, early detection, a trained workforce and family involvement are essential in providing the effective services and supports to a child with dual diagnosis and their family.

Recommendations

- Insist on interagency collaboration and the system of care model when awarding any grant, waiver, cooperative agreement, etc.
- Allow for a mental health/developmental disability child home and community based waiver (1915c).
- Develop a multidisciplinary training program for staff working with this population.

Assistant Secretary, Department of Health and Hospitals Office of Mental Health State of Louisiana

Comprehensive and Coordinated Systems of Care

The Developmental
Neuropsychiatry
Program
Louisiana Office of Mental Health
Cheryll Bowers-Stephens,MD,MBA

The Developmental Neuropsychiatry Program (DNP)

- System of Care serving youths who have both a psychiatric illness and a developmental disability
- The program has been in operation for over 10 years
- It was designed for youth that have not responded to traditional mental health and developmental services

History of Program Development

- Youths with Mental Illness and Developmental Disabilities were falling through the cracks and clogging up isolated service systems illequipped to address their needs
- Unacceptable given the prevalence: mental illness occurs in a higher percentage of persons with DD (3-6 times the rate in the general population)
- Rates of physical and sexual abuse are higher

History of Program Development

- Unique Challenge to service systems both with regard to diagnosis and treatment
- Correctly diagnosing MI in persons with DD is difficult
- Mental Health professionals are ill-equipped to make correct diagnosis
- Repeated misdiagnoses resulting in repeated ineffective treatments and ineffective pharmacotherapy

System of Care Overview

- Goal is to break the cycle of multiple hospitalizations and institutionalization by promoting community inclusion.
- Outpatient assertive community treatment program serving ages 2 to 22.
- Inpatient adolescent unit serving ages 13 through 18.
- ICF-MR Waiver Demonstration Project
- Long term follow up

DNP Service Model

- Learning-based, structured teaching approaches
- Encourages healthy, prosocial behaviors promoting social inclusion and reintegration or stabilization in the community
- Therapies adapted to the cognitive abilities and developmental needs of the individual.
- Family and School integrated into treatment

DNP Service Model

- Treatment promotes social skills development and builds upon the youths' personal goals and competencies
- Promotes interagency support and coordination

Evidence Based Practices

- Integration of behavioral and pharmacological interventions
- Functional Analysis and Behavioral Modification(Applied Behavioral Techniques; Cognitive Behavioral Therapy; Classical Behavioral Therapy)
- Continuity of Care
- Modified Linehan Approach (Dialectical Behavioral Therapy)
- Relaxation Training

Prevalence of Psychotropic Usage by Drug Class (Prior to Admission)

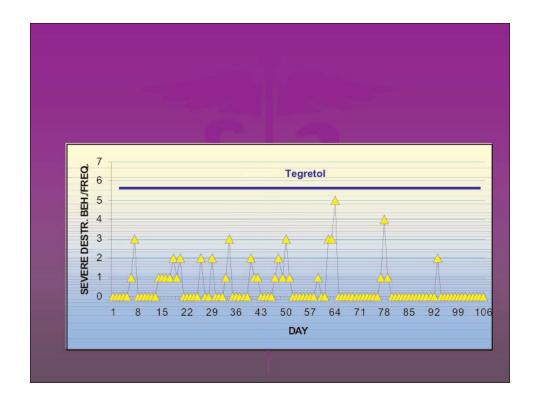
Drug Class	<u>Percentage</u>
Neuroleptics	85.0%
Mood Stabilizer	73.5%
Anti-Depressants (non-SSRI)	54.4%
SSRI's	55.8%
Anti-Depressants (combined)	78.2%
Psychostimulant	46.3%
Anxiolytics	24.5%
Anti-Convulsants	16.3%
Anti-Hypertensive	36.1%

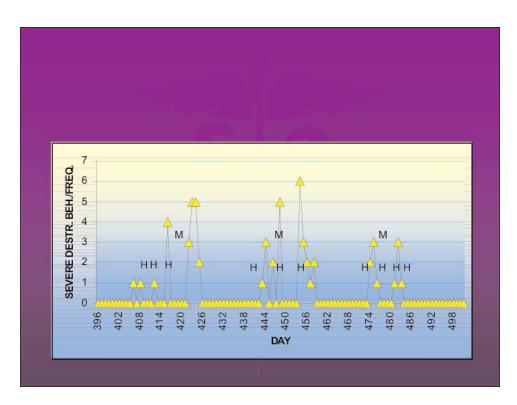
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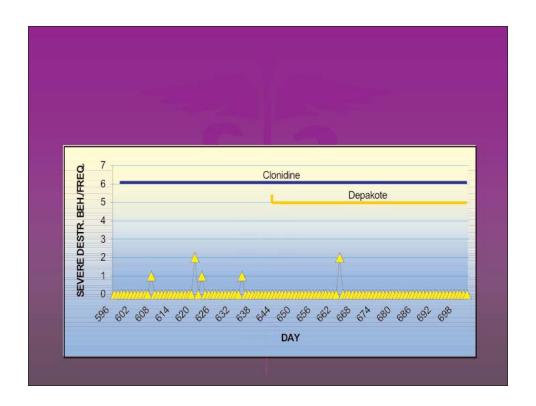
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Not Uncommon Errors in Diagnosis

- Psychosis based solely on invalid selfreport of auditory hallucinations
- PTSD diagnosed as Psychosis
- PTSD diagnosed as Conduct Disorder
- Bipolar Disorder diagnosed as Conduct Disorder







AACAP Work Group/1999

- Replacement Behavior Training
- Social Skills Training
- Disability Education
- Individual, Group and Family Therapy
- Behavioral Interventions
- Establish concrete goals
- Treatment delivered by clinicians with experience working with MR
- Concrete emphases (developmentally appropriate)

AJMR – Consensus Guidelines (May 2000)

- Applied Behavioral Techniques
- Cognitive Behavioral Techniques
- Classical Behavior Therapy

Behavioral Treatments of Depression

- Increasing Pos. Activities/Stimulation (Lewinsohn)
 - Increase Fun and Success Experiences
- Operant Approaches
 - · Positive Statements
 - Engagement in Activities
 - · Social Skills Training
- Cognitive Behavior Therapy
 - Modifications

MODIFIED DAILY MOOD LOG

Sad Thoughts	Happy Thoughts	
Nobody likes me. I don't have any friends.	I guess when I think deep down inside that there are a lot of people who do like me. (Lists them).	
I'm fat and ugly.	Other people say these things are nice about me. My hair, eyes, I'm pretty when I smile my eyes my personality	

Summary/CBT for persons with MR

- Simplify Basic Model of CBT
- Use Simple Explanations
- Use Simple Language
- Teach to Challenge Distorted Thinking
- Teach to Distract Self with Positive Cognitions
- Simplify Task by Refraining from Teaching Categories of Cognitive Distortions

Behavioral Treatments of Anxiety Disorders

- Phobia Studies
 - Peck (1977) and Jackson (1983)
- Standard Systematic Desensitization
 - · Establish Fear Hierarchy
 - · Teach SUDS Rating
 - Introduce Counterconditioning Element
 - Introduce Exposure
- Modifications for MR
 - · Participant Modeling
 - Reinforced practice
 - In Vivo Exposure

Behavioral Treatments of Anxiety Disorders (cont')

Obsessive Compulsive Disorder

Case Example

Gradual Negotiated Change
Exposure with Response Prevention
Positive R+ (Social/Tangible) of Goal
Attainment
Generalization to Home Setting

Behavioral Treatments of Anxiety Disorders (cont')

Post-Traumatic Stress Disorder

Hamilton (1994) - Managing Acute Distress

- 1. Relaxation training/Self-calming strategies
- 2. Removal from triggers
- 3. Cognitive Distraction

Protocol III

- 1. Counterconditioning Strategies
- 2. Imaginal Flooding
- 3. Planning for Possible Triggers
- 4. CBT

Borderline Personality Disorder

Linehan – Psychosocial Skills Training for Borderline Personality Disorder

- 1. Emotion Regulation Skills
- 2. Interpersonal Effectiveness Skills
- 3. Distress Tolerance Skills
- 4. Mindfulness Skills

AACAP Work Group Commentary (1999)

- Some clinicians target symptom suppression without regard for habilitative functioning
- Informed consent often overlooked
- Medication often is not integrated as part of comprehensive treatment plans
- Medications often don't match diagnosis
- Polypharmacy is overused
- There is often no active monitoring for side effects

Outcomes

- 207 patients served
- 184 served inpatient
- 60 served outpatient
- 23 outpatient only
- 123 inpatient only
- 37 both inpatient and outpatient

Outcomes

- 56% male and 44% female
- Mean age at admission is 15
- At admission 50% state custody

Diagnosis

- 75% have MR
- 25% Autism, PDD, LD, or met federal definition of DD
- 14% had autism or a PDD
- 35% mood disorder
- 25% anxiety disorder with PTSD most common
- 23% ADHD and 4% with thought disorder

Level of Care	Initial (177)		Curi (131	
Supported/IN	6	(3%)	27	(21%)
Parent/Family	86	(49%)	51	(39%)
Foster Family	25	(14%)	5	(4%)
Group Home	34	(19%)	21	(16%)
Residential	6	(3%)	6	(5%)
Hospital	6	(3%)	5	(4%)
Detention	3	(2%)	4	(3%)
ICF-MR	7	(4%)	11	(8%)
Eloped	4	(2%)	0	
Deceased	0		1	(1%)

Outcomes

- 86% in community/non-institutional settings
- 67% no re-hospitalization
- 74% have not served time in a correctional facility
- 88% have not been admitted to an ICF-MR
- 50% have had none of the above

Juvenile Justice Involvement in DNP Youth

147 INPATIENTS	Pre- Treatment	Post- Treatment
Legal Involvement	57%	36%
Arrests	46%	26%

Mental Health Treatment can Reduce Arrest Rates in this Population

Post treatment 90% of these youth had either no jail time or no jail time less than 30 days.

Lessons Learned

- These youth are at risk for substance abuse and dependence. Need specialized services.
- These youth are at risk of entering the juvenile justice system and adult corrections.
- These youth are institutionalized as adults.
- Failure to meet the needs of these youth is the most costly mistake that policymakers at both the state and federal level make.

PEGGY NIKKEL

Executive Director
UPLIFT (parent advocacy organization)
Casper, Wyoming

PANEL II: Comprehensive & Coordinated Systems of Care: Eligibility and Access Barriers

Family Perspective

Peggy Nikkel
Executive Director
UPLIFT
(Federation of Families for Children's Mental Health)
Casper, Wyoming

PEGGY NIKKEL

- Families struggle to access services
- Stigma
- Selective eligibility requirements
- Funding tied to eligibility categories

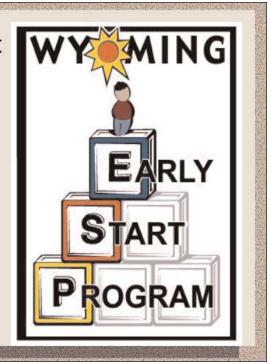
- Most programs and services are restricted to one population
- Disparity of services for mental health
- Screening instruments may not be comprehensive

PEGGY NIKKEL

- Lack of adequate training for service providers
- Lack of coordinated treatment team approach
- Families have to find the services and piece them together

Lack of consistent
early screening
and intervention
in Wyoming led
to the
development of
UPLIFT's

Wyoming Early Start Program



Steps to Enhanced Early Screening in Wyoming

- Family advocacy organization identifies gap in services.
- Secured funding to conduct community consensus building meetings regarding the need for early screening and identification for emotional disorders.

- Researched available screening instruments. Focused on the Early Screening Project: A Proven Child-Find Process and Ages and Stages: S/E
- Established partnership with screening instrument researcher/developer and TA consultants at Georgetown University.

- Developed Wyoming trainers to train early childhood providers in the use of research-based early screening and intervention models.
- Collaborated with existing early childhood state initiatives to include strong component in social and emotional development.

- Assembled funding partners to plan and implement annual statewide children's mental health conference with a focus on early childhood.
- All Wyoming child development centers and at-risk preschool programs now receive training in early screening and intervention.

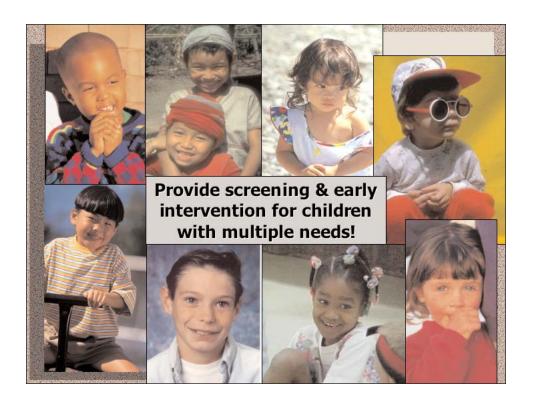
- Preschool children are being screened for delay in social/emotional development and referred for more intense early intervention services as needed.
- UPLIFT, Wyoming's Federation of Families for Children's Mental Health now serves as the Grant Administrator for all Wyoming's TANF At-Risk Preschool Programs.

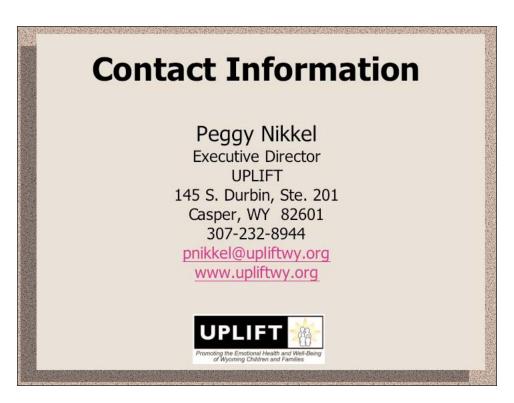
- Through continued collaborative activities, Wyoming's Comprehensive Early Childhood System Planning Grant will implement a multi-level professional development program with a focus on developmental and social/emotional components in the coming year.
- Family members CAN make a difference!

Recommendations

- Develop multiple access points for families.
- Increase access of non-clinical supports to families.
- Availability of services and supports should be based on need of child and family, not diagnosis.

- Provider training should include developmental disabilities and mental health.
- Integrate primary care with developmental disabilities and mental health.

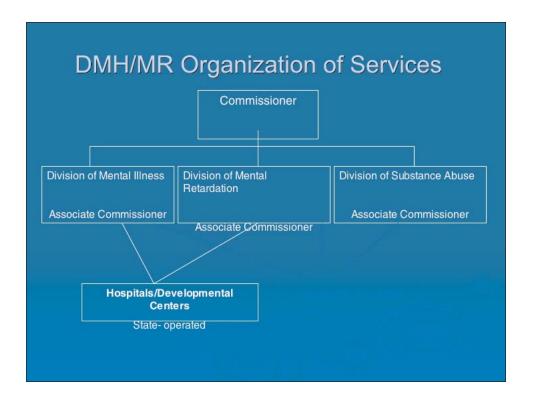




Directory, Office of Children's Services State of Alabama Department of Mental Health and Mental Retardation

Mental Health systems don't provide services that families need; they provide services that they get paid for.

Quote: Parent Advocate/ Georgetown Training Institute, San Francisco CA.



310 Boards

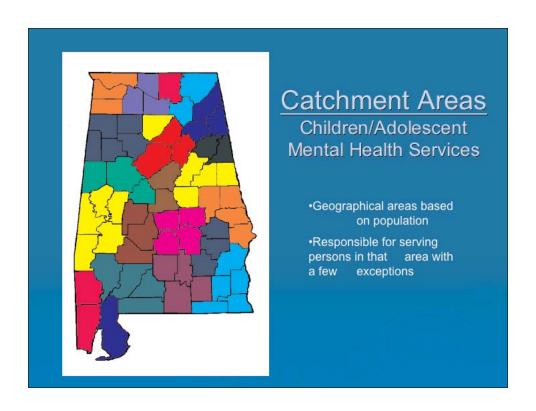
Public Corporations established to contract with DMH/MR and provide Planning, Studies, and Services for a given area.

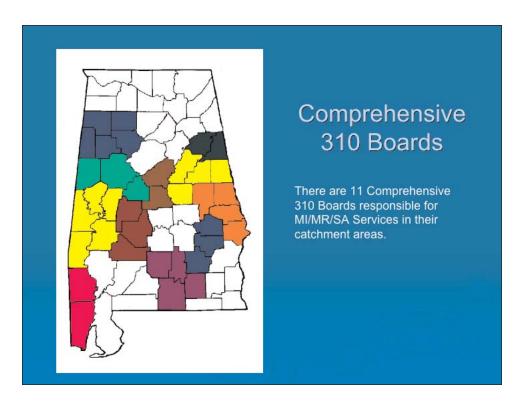
Comprehensive 310 Board

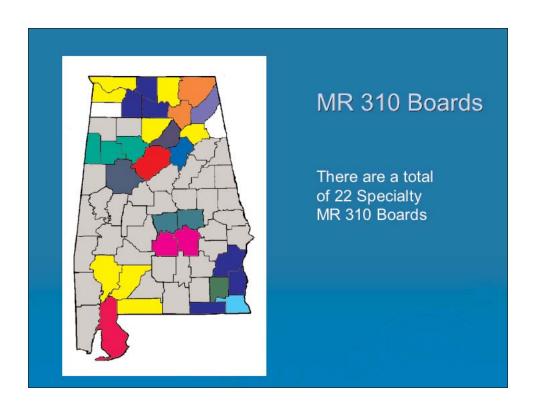
- Planning, Studying and Services for Mental Illness, Mental Retardation and Substance Abuse.
- May Contract one of these areas out.

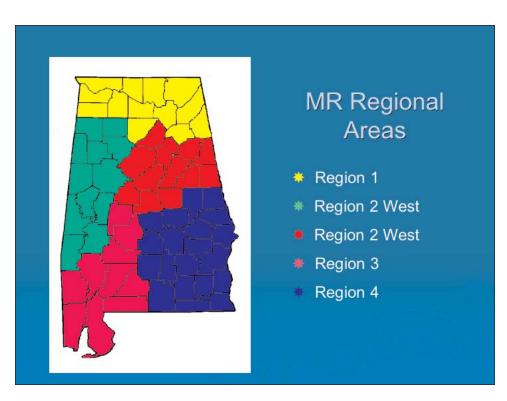
Specialty 310 Boards

 Provides Planning, Studying, and Services for one or more service areas









DMH/MR Division of Services for Children

- > MI Division (Seriously Emotionally Disturbed)
 - 2 FTEs for SED Services
- MR Division (Intellectual disabilities)
 - 1FTE (Early Intervention)
 - Children's Issues shared responsibility
- > SA Division (Substance abuse/ dependency)
 - No FTE dedicated to Adolescent Treatment Issues
- > 2001 Office of Children's Services
 - · 1FTE
 - Cross divisional responsibility/ emphasis on Co-Occurring (SED/SA and SED/MR)

Barriers to Access

- Fragmentation of services/ responsibility/ separate provider systems
- Historical funding challenges created service cultures of minimal responsibility
- > Availability of services/ specialized services in rural settings
- Stigma/ sometimes providers don't see past the ID symptoms for other needs
- Work force Issues

Shortage of service workers/ capacity Training needs Service Culture shifts

Barriers to Access Cont.

- Cross-certification of programs (Is it MR or MI? -sometimes tied to funding sources)
- Appropriateness of Services

Services delivery orientation creates different expectations Cognitive capacity to participate in certain programs (IOP, Inhome, residential)

Services Structure (O.P. 1 or 2x per month may not be intense enough) More info needed on Best Practices/ especially with this target group

Medication issues can be complicated

Lack of community resources/Residential services may not be specialized/leads to unsuccessful completion of programs/ longer LOS

Barriers to Eligibility

- State funds / most MR state funds support waiver services/ waivers not easily accessible
- Eligibility determined by what the professional determines as "primary issue"
- Collaboration between multiple systems not always reimbursed (case management)
- MR service system adult focused/ Waiting List

Barriers to Eligibility cont.

- Some Mental Health services have been historically unavailable to youth with ID, especially intensive inhome and residential type services.
- Barriers to eligible services in school or community can lead in involvement with juvenile justice system

2000 Children's Task Force: Recommendations to Alabama DMH/MR

- > 37 stakeholders (child-serving agencies, parents & advocates) recommended:
 - Priority given to children with multiple disabilities & other specialized treatment needs "Gap Kids"
 - Tobacco Settlement/Children First funding will not supplant current funding
 - Entry into the DMH/MR service system should be a single point of contact

Task Force further recommended:

- Pursue greater collaboration with other agencies to meet the needs children
- Priority given to community-based services
- Consolidate MH/MR children's services into a single organizational unit reporting directly to the Commissioner.

Promising Initiatives in Alabama for Children with ID and SED or SA needs

- Multiple Needs Child Legislation 1993
 - 4 mandated agencies (Mental Health/ Child Welfare/ Juvenile justice and Education)
 - Eligibility (need services of two or more agencies and at risk for out-of-home placement)
 - Braided funding
- Children's Task Force of 2000 Enhancement and development of services for "Gap Kids"
 - Establishment of Children's Office/ Director with responsibilities for this population
 - In-home teams
 - Crisis evaluation/ respite

Promising Initiatives cont.

- OUR Kids Initiative
 - Collaboration with Mental Health/ Child Welfare/ and Juvenile Justice to jointly fund community services for youth whose needs cross agency jurisdiction
 - Each service can serve children with ID and SED.

 Pooled Funding
- Mental Health Juvenile Court Liaisons
 - 22 community mental health clinicians/ youth involved with juvenile justice and have MH/ SA/ or MR needs
- Co-Occurring (MH/SA and Juvenile Justice) Pilot Project for screening/assessment of youth and referral to evidence-based interventions

Pooled funding

Recommendations

- Follow the momentum generated by Co-Occurring (MH/SA) initiatives when creating new service paradigms and integrated models of care (State & Federal)
 - What is the primary diagnosis/issue, may not be the best question for children.
- Federal grant initiatives to highlight or target this population to build capacity as well as provide services/ systems need new competencies
- Advocate for federal incentives to have professionals enter front-line child serving mental health fields (i.e. student loan relief)

Recommendations Cont.

- Identify and remove federal barriers to braiding and blending of funds within and between agencies.
- Increase training opportunities for multi-level issues (financing – best practices) that encompass this issue
- Increase Federal-State partnerships with Education and MH to work more collaboratively on school-based services
- Federal Medicaid cuts will have devastating effects on efforts to transform systems at the state level
- Identify Best practices for this population and encourage reporting of data on Evidence-Based Practices that have significant differences with this population

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Director, Ohio Department of Mental Retardation and Developmental Disabilities

Comprehensive and Coordinated Systems of Care: Eligibility and Access Barriers

Kenneth Ritchey, Director
Ohio Department of Mental
Retardation and Developmental
Disabilities

Ohio's Current System

- Department level agencies
- 88 CBMRDD
- 51 Mental health boards
- Local authority
- Local taxes

The "State" of Ohio

- Services were fragmented
- Systems did not talk to each other
- Each system "blamed" the other
- "Primary diagnosis"
- Virtually no shared funding

Ohio's Efforts to Coordinate Care

- Directors Ritchey and Hogan(ODMH) establish MI/MR Advisory Board to:
- Identify Best Practices
- Recommend ways to overcome barriers between systems
- Train staff in both systems.

More Efforts

- Interagency Agreement between ODMRDD and ODMH
- Ohio's Coordinating Center of Excellence for MR/MI
- Professorship in MR/MI at Wright State University funded by ODMRDD, ODMH, Montgomery CBMRDD, and Montgomery County Board of Alcohol, Drug Addiction, and Mental Health Services
- ODADAS has become a part of CCOE Advisory Board.
- Currently developing an interagency agreement between ODMRDD and ODADAS

Access to Better Care

- Leading adolescent health challenge
- Leading cause of death among teens via suicide
- Major driver of school failure
- Major challenge in Ohio's child welfare system
- Major challenge in juvenile justice

ABC Recommendations

- Focus prevention efforts
- Intervene earlier with children and their families
- Reduce treatment gaps and empower parents so children with behavioral disorders do not fall through the cracks, and families do not have to trade custody for care.

Ohio Autism Taskforce

 HB 95 required that OAT investigate the increasing incidence of autism and to determine what gaps exist in the delivery of service.

Autism Taskforce Recommendations

- Establish a standard practice of autism diagnosis
- Regional disparity of services be eliminated.
- Maintain or increase funding for programs
- Quality and quantity of family support services increased
- Autism waiver should be submitted to CMS

Screening and Eligibility

- Federal Eligibility Determination
- COEDI (MRDD System)
- DSM IV Diagnosis

Barriers

- Qualified and trained staff in both systems
- Housing
- Employment
- Lack of waivers for mental health services
- Lack of waivers for children

More Barriers

- Funding in silos
- Parents relinquish custody
- Waiver match
- Significant barriers exist as a result of the institutional bias of Medicaid.

Recommendations for Federal government

- Create incentives to serve children in the community.
- Medicaid waivers for services across systems.
- National Centers of Excellence
- ICF/MR should not be required to be offered but should be last resort.
- Funding should be same between ICF/MR and waivers.

Human Service Collaborative washington, DC

State-Community Response to Barriers for Children with Co-Occurring Developmental Disabilities and Emotional/Substance Abuse Disorders

Comprehensive and Coordinated Systems of Care:
Addressing Financing Challenges

Sheila A. Pires Human Service Collaborative

April 27, 2005

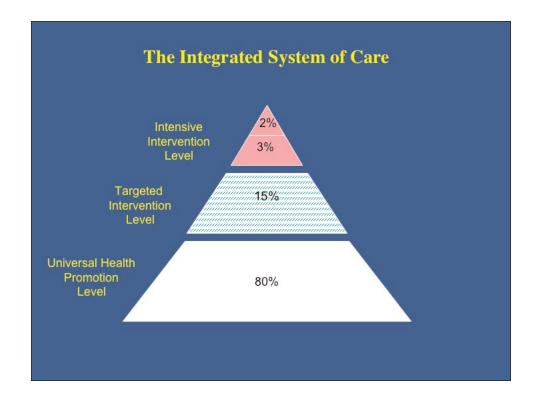
Office on Disability
U.S. Department of Health and Human Services
Rockville, Maryland

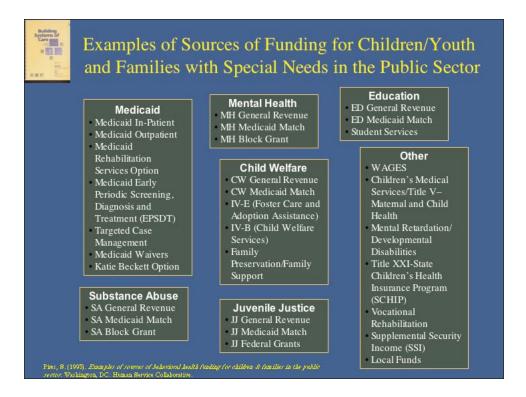
Building Systems of Care

The Total Population of Children/Youth and Families Who Depend on Public Systems

- Children/youth and families eligible for Medicaid
- Children/youth and families eligible for the State Children's Health Insurance Program (SCHIP)
- Poor and uninsured children/youth and families who do not qualify for Medicaid or SCHIP
- Families who are not poor or uninsured but who exhaust their private insurance, often because they have a child with a serious disorder
- Families who are not poor or uninsured and who may not yet have exhausted their private insurance but who need a particular type of service not available through their private insurer and only available from the public sector.

Pires, S., 2003. Building systems of care: A primer. Washington, D.C.: Georgetown University





Fundamental Challenge to Building System of Care

No one system controls everything.

Every system controls something.

Pires, S. 2004. Human Service Collaborative. Washington, D.C.

Examples of Medicaid Promise/Reality

EPSDT

- Broadest entitlement
- •Cost concerns so states use various ways to control access through EPSDT

Home and Community-Based Waivers

- •Flexibility, broader coverage, waiver of income limits and comparability
- •Alternative to hospital-level of care but RTC may be the issue
- •Cost and management concerns so limited to certain number

Targeted Case Management

- •Can be targeted to high need populations (e.g., co-occurring)
- •Not sufficient without other services
- •Administrative rulings from CMS?

Some Medicaid Challenges Relevant to Children with Co-Occurring Disorders and Their Families

- •Service definitions, esp. for home and community-based
- •15-minute billing increments vs. case rates, esp. for evidence-based services
- •Billing for interagency coordination
- •Billing for team meetings
- •Billing for services to family (as opposed to identified child)
- •Billing for non traditional services and supports
- •Administrative rulings (e.g., coverage of non-psychiatric medical services in psychiatric hospitals under Psych Under 21 Option)
- •States/localities must generate match and manage costs
- •Not every child is eligible for Medicaid

Lots of Medicaid "Urban Legends" <u>But</u> <u>If Something Exists Somewhere</u>, It's Possible Elsewhere

Covering Parents as Care Managers: KN, NJ

Covering Respite in Medicaid FFS: NY

Covering Wraparound Team Process: NE

Covering Non Traditional Services (i.e. traditional Native healers): AZ

Covering Independent Living Services: SC

SOURCE	SYSTEM	DESCRIPTION
Federal/ State	Mental Health	General fund, Medicaid (including FFS/managed care/waivers) federal mental health block grant, redirected institutional funds and funds allocated as a result of court decrees
	Child Welfare	Title IV-B (family preservation), Title IV-B (foster care services), Title IV-E (adoption assistance, training, administration), and technical assistance and in-kind staff resources
	Juvenile Justice	Federal formula grant funds to states for juvenile justice prevention, state juvenile justice appropriations, and juvenile courts.
	Education	Special education, general education, training, technical assistance, and in-kind staff resources
	Governor's Office/Cabinet	Special children's initiatives, often including interagency blended funding
	Social Services	Title XX funds and realigned welfare funds (TANF)
	Bureau of Children with Special Needs	Title V federal funds and state resources



Diversity of CMHS Grant Sites Funding (continued)				
SOURCE	SYSTEM	DESCRIPTION		
State	Health Department	State funds		
	Public Universities	In-kind support, partner in activities		
	Department of Children	In states where child mental health services are the responsibility of child agency, not mental health, sources of funds similar to above		
	Vocational Rehabilitation	Federal- and state-supported employment funds		
	Housing	Various sources		
Local	County, City, or Local Township	General fund		
	Juvenile Justice	Locally controlled funds		
	Education	Courts, probation department, and community corrections		
	County	May levy tax for specific purposes (mental health)		
	Food Programs	In-kind donations of time and food		
	Health	Local health authority-controlled resources		
	Public Universities and Community Colleges			
	Substance Abuse	In-kind support		



Diversity of CMHS Grant Sites Funding (continued)

SOURCE	SYSTEM	DESCRIPTION
Private	Third Party Reimbursement	Private insurance and family fees
	Local Businesses	Donations and in-kind support
	Foundations	Robert Wood Johnson, Annie E. Casey, Soros Foundation, and various local foundations
	Charitable	Lutheran Social Services, Catholic Charities, faith organizations, homeless programs, and food programs (in-kind)
	Family Organizations	In-kind Support

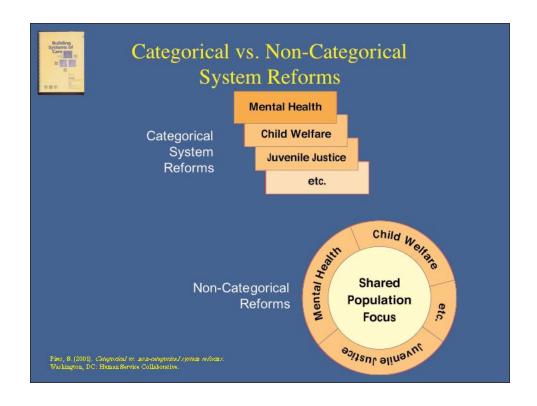
Koyanagi, C. & Feres-Merchant, D. (2000). For the long haul: Maintaining systems of care beyond the federal investment. Systems of care. Promising practices in children's mental health, &: American Institutes for Research, Center for Effective Collaboration and Practice: Washington, D.C.



Definition of a System of Care

A system of care incorporates a broad array of services and supports for a population of children and families that is organized into a coordinated network, integrates care planning and management across multiple levels, is culturally and linguistically competent, and builds meaningful partnerships with families and youth at service delivery, management, and policy levels.

Pires, S. (2002). Building systems of over 14 primer. Washington, D.C.: Human Service Collaborative





Financing Strategies to Support Improved Outcomes for Children & Families

FIRST PRINCIPLE:

System Design for Target Population Drives Financing

REDEPLOYMENT:

- ·Using the Money We Already Have
- The Cost of Doing Nothing
- Shifting Funds from Deep End Treatment to Early Intervention and Home and Community-Based
- Moving Across Fiscal Years

REFINANCING:

- Generating New Money by Increasing Federal Claims
- •The Commitment to Reinvest Funds for Families and Children
- •Foster Care and Adoption Assistance (Title IV-E)
- Medicaid (Title XIX)

Adapted from: Friedman, M. (1995). Financing strategies to support improved outcomes for abiliden. Center for the Study of Social Policy: Washington, D. C.



Financing Strategies to Support Improved Outcomes

RAISING OTHER REVENUE TO SUPPORT FAMILIES AND CHILDREN:

- Donations
- Special Taxes and Taxing Districts for Children
- Fees and Third Party Collections Including Child Support
- Trust Funds

FINANCING STRUCTURES THAT SUPPORT GOALS:

- Seamless Services: Financial claiming invisible to families
- Funding Pools: Breaking the lock of agency ownership of funds
- Flexible Dollars: Removing the barriers to meeting the unique needs of families
- Incentives: Rewarding good practice

Friedman, M. (1995). Financing strategies to support improved outcomes for abiliden. Center for the Study of Social Policy: Washington, D.C.

New Generation of Managed Care

and family/consumer

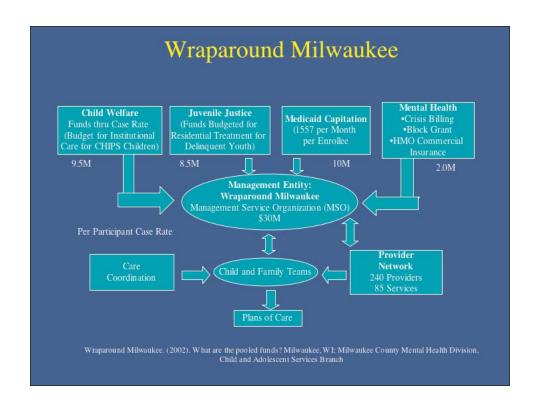
•Integrates payer, manager and provider ^ of care into an integrated delivery system

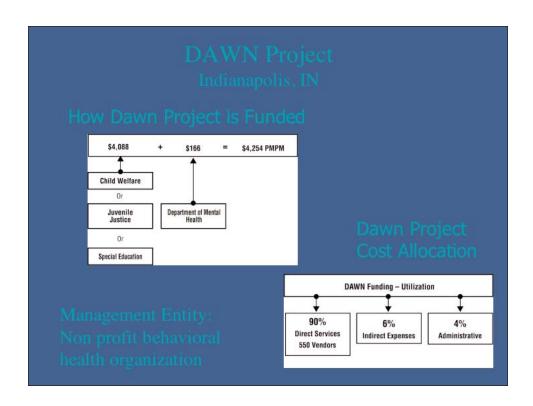
services and supports

•Focuses on a delivery system that provides (treatment) ^ for a defined *children and families*population of (patients) ^ in a defined geographic area

- •Provides continuity of care over a full continuum of care through the period a child and family needs services entire (episode of the patient's illness) ^
- •Has a results orientation that measures not only the process of care, families/ consumers services and supports but the satisfaction of (patients) ^ and the outcome of the ^ (treatment) provided

Adapted from MEDCO Behavioral Health Care Corporation, 1994





Life Domains • Service coordination plans, Health/medical including safety and crisis Safety/crisis plan Family/relationships · Broad array of treatment and Educational/vocational supportive services Psychological/emotional • Extensive provider network, Substance abuse paid fee for service Social/recreational Daily living Cultural/spiritual

Financial/legal

Dawn Service Array

Behavioral Health

Behavior management Crisis intervention

Day treatment

Evaluation

Family assessment

Family preservation

Family therapy

Group therapy

Individual therapy

Parenting/family skills training

Substance abuse therapy, individual and

group

Special therapy

Psychiatric

Assessment

Medication follow-up/psychiatric review

Nursing services

Mentor

Community case management/case aide

Clinical mentor

Educational mentor

Life coach/independent living skills

mentor

Parent and family mentor

Recreational/social mentor

Supported work environment

Tutor

Community supervision

Dawn Service Array, Continued

Placement

Acute hospitalization

Foster care

Therapeutic foster care Group home care

Relative placement

Residential treatment

Shelter care

Crisis residential

Supported independent

living

Respite

Crisis respite Planned respite

Residential respite

Service

Coordination

Case management Service coordination

Intensive case management

Other

Camp

Team meeting Consultation with other

professionals

Guardian ad litem

Transportation Interpretive services

Discretionary

Activities

Automobile repair

Childcare/supervision

Clothing

Educational expenses

Furnishings/appliances

Housing (rent, security

Medical

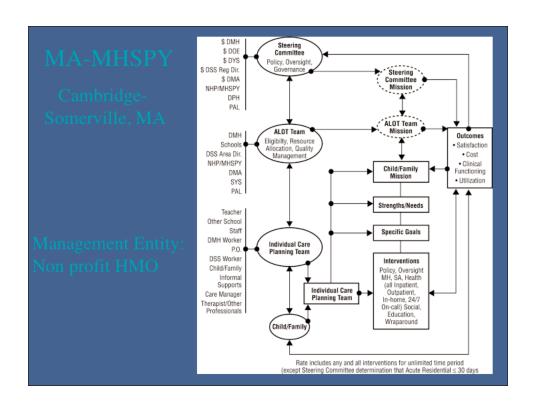
Monitoring equipment

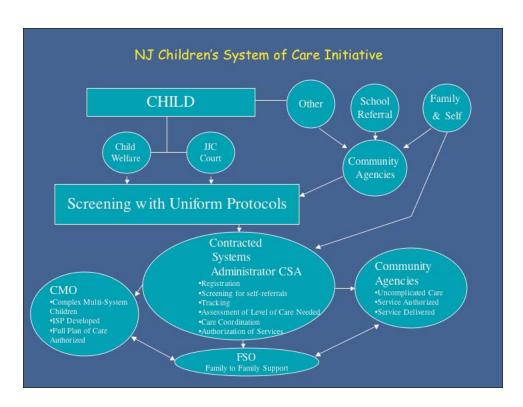
Paid roommate

Supplies/groceries

Utilities

Incentive money





OUTCOMES (Milwaukee Wraparound)

- •60% reduction in recidivism rates for delinquent youth from one year prior to enrollment to one year post enrollment
- •Decrease in average daily RTC population from 375 to 50
- •Reduction in psychiatric inpatient days from 5,000 days to less than 200 days per year
- •Average monthly cost of \$4,200 (compared to \$7,200 for RTC, \$6,000 for juvenile detention, \$18,000 for psychiatric hospitalization

OUTCOMES (MA-MHSPY AND OTHER MA-WRAPAROUND)

- •Reduction in use of prescription meds
- •Reduction in overall cost
- •Improved functioning at home, school, and in the community
- •Parents feeling more confident and capable in managing their children's challenging behaviors
- •Reduced utilization of out-of-home care

Outcomes (Monroe County Youth and Family Partnership – Rochester, NY)

- •Year One cost savings of \$3,189 pmpm \$38,274 annual
- •Year Two cost savings of \$3,813 pmpm \$45,751 annual
- •Year One CAFAS score improvements for 69% of youth
- •Year Two CAFAS score improvements for 71% of youth

 $Levison-Johnson, J.\ 2004.\ Using\ data\ for\ continuous\ quality\ improvement\ in\ an\ integrated\ setting.$ Coordinated Care Services, Inc. Rochester, NY

Common Elements of Re-Structured Systems

- ✓ Identified target population, costs associated with population, funders
- ✓ Locus of accountability (and risk) for target population
- ✓ Single pathway to services for target population
- ✓ Strengths-based and individualized service planning and care monitoring (e.g., wraparound approach)
- ✓Intensive care management

continued ...

Pires, S. 2004. Human Service Collaborative. Washington, D.C.

Common Elements of Re-Structured Systems

- ✓ Flexible financing and contracting arrangements (e.g., case rates, qualified provider panel fee-for-service)
- ✓ Broad provider network: sufficient types of services and supports (including natural helpers)
- ✓ Combined funding from multiple funders (e.g., Medicaid, child welfare, mental health, juvenile justice, education)
- ✓ Real time data across systems to support clinical decision-making, utilization management, quality improvement
- ✓ Outcomes tracking child/family level, systems level continued...

Common Elements of Re-Structured Systems

- ✓ Values-based systems/Family and youth partnership
- ✓ Utilization management
- ✓ Mobile crisis capacity
- ✓ Judiciary buy-in
- ✓ Re-engineered residential treatment centers
- ✓ Shared governance/liability
- ✓ Training and technical assistance

Pires . S. 2004. Human Service Collaborative. Washington . D.C.

Infrastructure-Building Technical Assistance Needs

- •How to analyze expenditures and utilization across systems
- •How to use risk-based financing approaches to re-direct expenditures from "deep-end" to home and community-based (e.g., how to build case rates, develop risk pools)
- •How to collapse budget structures to create flexibility across line items
- •Medicaid state plans (e.g., benefit design, service definitions, rate structures)

Pires, S. 2004. Human Service Collaborative. Washington, D.C.

Infrastructure-Building Technical Assistance Needs

- •How to develop purchasing collaboratives to support a coordinated financing approach (NM)
- •Purchasing strategies and reimbursement mechanisms; paying for non traditional supports and for family and sibling supports
- •How to develop clinical practice guidelines and quality monitoring systems tied to cross-system outcomes (MI, TX, NJ)
- •How to develop utilization management systems
- Cost/benefit data

Pires, S. 2004. Human Service Collaborative. Washington, D.C.

Infrastructure-Building Technical Assistance Needs

- •Planning (strategic planning, population definition and sizing, capacity issues, stakeholder involvement, etc.)
- •Cultural and linguistic competence supportive state infrastructure
- •HRD strategies
- •Governance (and liability) structures
- •Provider issues (e.g., re-engineering RTCs, natural helping networks, evidence-based capacity, etc.)

Pires, S. 2004. Human Service Collaborative. Washington, D.C.

Infrastructure-Building Technical Assistance Needs

- •Data (MIS) systems
- Social marketing strategies
- •Information dissemination strategies (e.g., web-based)
- •Public health approaches to youth with co-occurring disorders (e.g., tracking incidence, screening, public education, stigma reduction, prevention, etc.)
- •Integrating related reform initiatives
- How to use technical assistance and consultants strategically Pires, S. 2004. Human Service Collaborative. Washington, D.C.



To Obtain Copies of *Building Systems of Care: A Primer* Contact:

Mary Moreland, Publications Manager Georgetown University National Technical Assistance Center for Children's Mental Health 202 687-8803

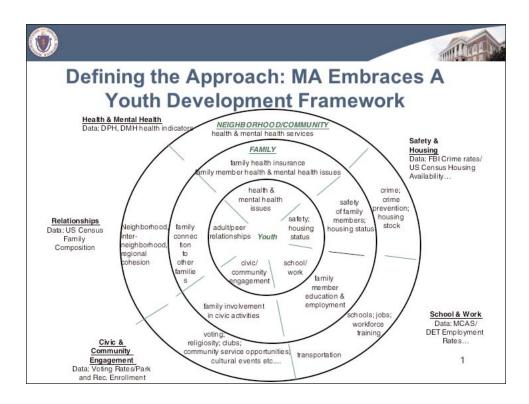
E-mail: <u>deaconm@georgetown.edu</u>

For Further Information About Building Systems of Care, Contact:

Sheila A. Pires Human Service Collaborative 202 333-1892

E-mail: sapires@aol.com

Deputy Assistant Secretary
Office of Children, Youth and Families
Commonwealth of Massachusetts

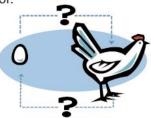






Defining the Population:

A classic problem of:



- ❖Which Trumps Which DD or SED?
- ❖Relevant for eligibility and treatment decisions. Particularly important when youth "ages out" of child system into adult services.





Defining Medicaid Covered Services

- New services developed- no guidance from CMS
- If one state covers a service using Medicaid dollars, does that mean it is a covered service? Medical Necessity Criteria Rules.
- Federal Waivers/ cost neutrality factor



Defining Terms: Rehabilitation versus Habilitation & Early Intervention as a Hybrid

Habilitation- The cause of the condition

Rehabilitation- treatment to optimum functioning- covered by Medicaid



Early Intervention- Rehabilitation services covered by Medicaid

4





Defining Appropriate Care: Treating Youth with SED and DD is a Specialty

Youth Hospitalized

- Specialty Units
- 1:1 Specialing



Differential Diagnosis

Limited ability to describe problems



Defining Trained Staff: NCQA

Utilizing Services across systems-credentialing barriers

Training Programs specific to this population



Incentives to providers to develop specialty services

6





Defining Responsibility: When Does The School Day End?

- •After school services identified by families as most needed service
- Respite
- •Children awaiting a disposition regarding a cost share



Defining Payment Options: Case Rates

- Flexibility with Case Rate
- Outcomes Driven
- ❖Need to itemize services
- Lack of Direction



8





Defining The Way We Do Business: Examples of Best Practices



Care Coordination/Targeted Case Management

Covered but under great federal scrutiny

Individualized Flexible Plan (and only one!)

- ❖Team meetings/ administrative expense
- ❖Data systems for sharing the IFP

Involve Families in Planning

❖Pay for time/daycare etc.



Defining Expectations: Collaboration

Planning Review Teams

- ❖Best efforts at collaboration _
- Family Participation in the design
- Attempt to be responsive to families bumping multiple systems utilizing Systems of Care Principles _
- ❖Major drawback- no new \$\$\$

DOE/DMR Partnership

❖Family supports to avoid residential placement

10





Blended Funding System of Care Model:

Youth with Co-Occurring Disorders Enrolled in Systems of Care Pilots

Case Example:







Defining the Future: Grant/Learning Opportunities

Provide funding for programs to provide wrap around services to children (and their families) with SED and DD

Provide information on best practices for the treatment of this population including regular guidance as the science evolves

Link actions, across HHS agencies, to the New Freedom Commission report. Current actions undermine the principles established in it.

Clarify Medicaid covered services for kids under EPSDT

Director, Allegheny County Department of Human Services Pittsburgh, Pennsylvania



State-Community Response to Barriers for Children with Co-occurring Developmental Disabilities and Emotional/Substance Abuse Disorders

Comprehensive and Coordinated Systems of Care: Addressing Financial Challenges

Marc Cherna, Director

Allegheny County Department of Human Services



Allegheny County Statistics

- · 28th largest county in the nation
- · 1.3 million residents
- 130 municipalities
- 91 neighborhoods in the City of Pittsburgh





Allegheny County Statistics

Persons Served Annually - Approx. 250,000

Total Staff - approximately 1,100

Service Providers - Approximately 400

· 820 contracts for over 1,800 discrete services

Total Budget - \$757.4 million

(55% federal, 42% state, 3% county)

Funding Sources - 80

 each with separate laws, regulations, and reporting requirements



Executive Office

Program Offices

- Area Agency on Aging
- · Office of Behavioral Health
- · Office of Children, Youth and Families
- Office of Community Services
- Office of Mental Retardation/ Developmental Disabilities

Support Offices

- Office of Administration
- · Office of Community Relations
- · Office of Information Management



Department of Human Services Active Caseload

Children with co-occurring disabilities served in multiple systems

- •CYF MH = 2210
- •MH D&A = 798
- •MH MR/DD = 728
- •CYF EI = 480
- •CYF D&A = 311
- •CYF MH D&A = 246
- •CYF MR/DD = 117
- •CYF MH MR/DD = 84
- •D&A MR/DD = 9



Department of Human Services Children's System

- 63% Served by more than one system
- · 0 Children placed out of state
- Traditional and non-traditional services
 Heavy family involvement
- · Parents don't have to relinquish their rights
- County Interagency process
- · Multi-System Rapid Response
- · Children's Cabinet



Department of Human Services County Interagency Process

Systems, providers, and consumers and their families are brought together to ensure that the comprehensive needs of the individual are addressed through a full continuum of services and tangible assistance when needed.

Reduces system fragmentation, discontinuity of service and conflict/competition over scarce resources.

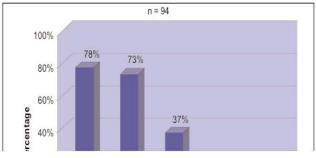
County Interagency process is always able to arrive at recommendations with families.



During FY '03/04:

- 109 Interagency meetings were held for 94 individual children/adolescents.
- Of the 109 Interagency meetings, only 10 required referrals to the multi-system team for additional planning.

Department of Human Services County Interagency Multi-system Involvement



85% of those children /adolescents referred for County Interagency Review have multisystem involvement.



Multi- System Rapid Response Team

Function

- · Identify gaps in service, practice, and policy
- Find or create solutions
- Research
- Negotiate
- Respond
- · Forecast-tracking & identifying trends
- Plan
- Communicate
- Cross-System Train/Consult
- Make decisions
- Determine best course of action



Multi- System Rapid Response Team

Statistics

- •8 Cases reviewed in fiscal year 2001-2002
- •14 Cases reviewed in fiscal year 2002-2003
- •13 Cases reviewed in fiscal year 2003-2004

Although the number of cases referred yearly is generally small, the complexities of their needs are great.



Multi- System Rapid Response Team

All of the children have co-occurring disorders. Some of the more prevalent diagnoses include:

- 76% have MR/DD;
- 53% have an impulse control disorder;
- 53% have a mood disorder:
- · 46% have an anxiety disorder;
- · 38% have attention deficit disorder; and
- 38% have a pervasive developmental disorder

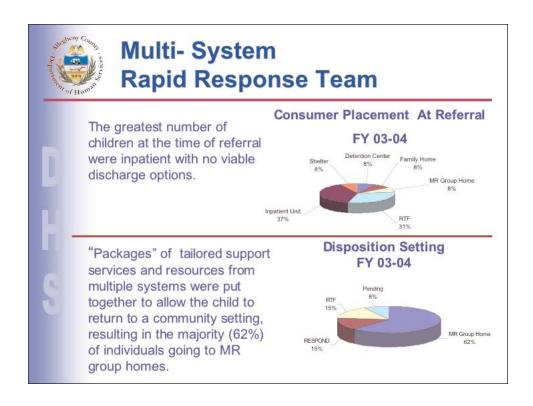
(Diagnoses are not mutually exclusive.)

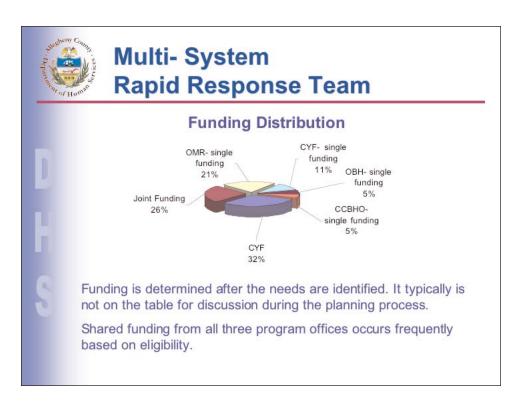


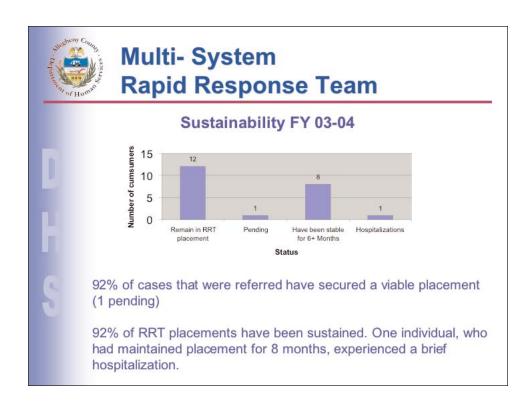
Multi- System Rapid Response Team

All 13 children/adolescents served by the Multi-System Team are multi-system involved.

- 8% of the cases referred are involved in 4 systems
- 62% of the cases referred are involved in 3 systems.
- 31% of the cases referred are involved in 2 systems





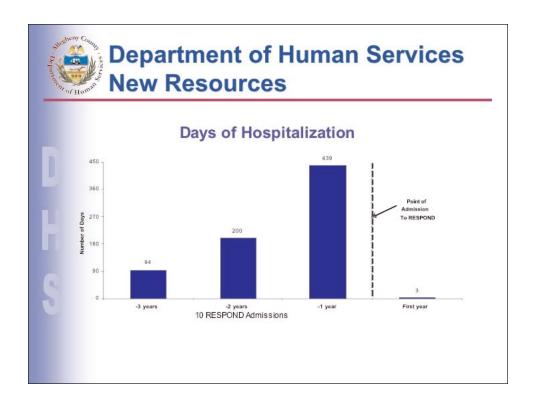




Department of Human Services New Resources

RESPOND

- · 10 admissions to the program
- 5 Successful discharges to community settings- with no hospital admissions post-discharge.
- Only one individual of 10 experienced a 24-hour hospitalization as a resident of RESPOND
- 5 Individuals who had failed or plateaued in RTF level of care demonstrated progress/success in this unique level of care
- · Medications have been reduced for each individual
- Better coping skills have been obtained as evidenced by the reduction in aggressive behaviors for each resident
- Successful discharge planning for all residents
- · Better systems collaboration and communication



Department of Human Services Integrated Children's Plan

New requirement of Pennsylvania Department of Public Welfare in 2004

 Brings together key stakeholders in child welfare, drug & alcohol, mental health and mental retardation systems

Focus on launching and expanding cross-systems initiatives that don't fit neatly into existing silos

 Examples: Building common information systems, providing coordinated case management services, serving children with physical disabilities

Process currently includes child welfare budget only

 Possibility of folding in mental health and mental retardation budgets for children in the future



Department of Human Services Recommendations

Increase Block Grants

- Undefining the money allows funds to be moved where they are needed.
- Gives consumers the ability to "One Stop Shop" for services.
- Reduces red tape associated with eligibility requirements.
- Enables holistic service delivery truly "wrapping" services around the individual.
- Enables provision of services to at-risk youth without requiring a diagnostic label.



Department of Human Services Recommendations

Eliminate insurance companies cost shift to government.

- MH and D&A parity
- · Reimbursement for autism services
- Reduction of reliance on medical necessity criteria

Medicaid behavioral health care carve out.

MR Medicaid waivers



Department of Human Services Recommendations

Federal government needs to reduce demonstration grants.

- Costs applicants a lot of time and money very few grants
 - · Match is a problem
- · Expand on what works
- Ongoing funding

Coordination amongst government entities.

Reduce unfunded mandates.

HIPAA requirements huge cost to state and local government



Department of Human Services Recommendations

Consistent priorities between government entities.

- CSFR process
 - Program improvement plans

Consistent rules and regulations between government entities.

Consistent confidentiality regulations.

Focus on outcomes.

Focus on consumer satisfaction.

Resist pressures of special interests.



Department of Human Services Perspective on Funding

Demand for human services in Allegheny County (just like in the rest of the country) continues to outweigh the supply.

As a result, any new funding that enters the system tends to be used to satisfy urgent needs and not system reform.

Dollars for prevention activities, the best way to save high costs down the line, are especially hard to come by.